TABLE 2

Difference between clinical and autopsy diagnosis of lung cancer

Principal author	Year of paper	Numbers of cancers Clinical diagnosis conf A	unconf B	Seen at autopsy only C	False negative rate (%) 100C/(A+C)	False positive rate (%) 100B/(A+B)	Under estimation factor (A+C)/(A+B)
Sehrt	1904	6	-	172	96.6	-	Large
Wells	1923	1	-	10	90.9	-	Large
Swartout*	1934	20	-	6	23.1	-	-
Swartout*	1940	71	-	28	28.3	-	-
Pohlen	1942	200	12	121	37.7	5.7	1.51
Munck	1952	14	2	6	30.0	12.5	1.25
O'Neal	1957	254	-	47	15.6	-	-
Waaler	1958	33	-	32	49.2	-	-
Gwynne	1965	46	2	26	36.1	4.2	1.50
Heasman	1966	227	111	190	45.6	32.8	1.23
Takeda I**	1967	179	-	166	48.1	-	-
Takeda II**	1967	1488	(305)	788	34.6	(17.0)	(1.27)
Willis	1967	43	9	28	39.4	17.3	1.37
Rosenblatt	1971	27	34	0	0.0	55.7	0.44
Bauer	1972	227	-	219	49.1	-	-
Britton	1974	9	1	7	43.8	10.0	1.60
Ehrlich	1975	25	5	9	26.5	16.7	1.13
Hartveit	1977	39	4	10	20.4	9.3	1.14
Waldron***	1977	37	11	>19	>33.9	22.9	>1.17
Hartveit	1979	71	5	35	33.0	6.6	1.39
Cechner	1980	260	38	117	31.0	12.8	1.27
Sandritter	1980	60	-	9	13.0	-	-
Cameron	1981	88	15	46	34.3	14.6	1.30
Gobbato	1982	-	-	-	37.0	-	-
Asnaes	1983	16	0	4	20.0	0.0	1.25
McFarlane	1986	103	-	37	26.4	-	-
Mollo	1986	72	27	62	46.3	27.3	1.35
Reid	1987	11	4	9	45.0	26.7	1.33
Grundmann I	1991	191	56	-	-	22.7	-
Grundmann II****	1991	350	82	-	-	19.0	-

* Respiratory cancer

** Two studies, deaths in 1948-52 (I) and in 1958-62 (II). For study II B includes only cases misdiagnosed as another cancer

*** C only includes those deaths reported clinically to be from another cancer

**** Two studies, deaths in 1961-70 (I) and in 1978-87 (II).

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studies by Sehrt and Wells suggest that during the first quarter of the century lung cancers were very substantially underdiagnosed clinically.

4. DEATH CERTIFICATES

4.1 Failure to register or certify deaths

Not all deaths need be registered or certified. This is illustrated by the study of Dean (1979) who obtained 2000 names of men and women from burial records in parishes in the west of Ireland in 1971. These were checked against the register of births and deaths: 6.5% had been neither certified nor registered and a further 7.5% had been registered but not certified.

4.2 Reasons for errors in death certificates

Angrist (1958) pointed out a basic problem in death certificates that is not related to any code or classification of disease. He observed that "during the very first year of use of the sealed confidential certificate in Manhattan (where no one but the physician and the certification clerk ever saw the certified cause of death) there was a 10 per cent drop in recording of arteriosclerotic heart disease and a corresponding increase in recording of alcoholism, syphilis, cancer and insanity on death certificates.

Bourke and Hall (1968) describe a study conducted in Ireland in 1963 based on 10,204 domiciliary death certificates relating chiefly to senility, diseases of the circulatory system, and vascular lesions of the central nervous system. It was shown that there was a

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clear tendency for older certifying doctors to be more likely to use the terms "other myocardial degeneration" and "senility without mention of psychosis".

Dean (1969) carried out a study of death certificates in the Republic of Ireland, concluding that there was a need for accurate certification of the cause of death and far more autopsies. He noted that there were too many death certificates in which the given cause of death was a vague term such as "senility" or "myocarditis" and that a high proportion of deaths in the rural areas of Ireland had not been certified by a doctor at all. Certain areas were particularly responsible for inaccurate certification. "For instance, in one hospital every death studied was certified as a death from myocarditis, including eight deaths in one week".

Adelstein (1978) described four reasons for errors in death certificates:

(i) doctors may conceal what they consider embarrassing conditions such as alcoholism

(ii) coroners usually omit psychological antecedents when certifying suicide

(iii) coroners' pathologists sometimes do not use the standard form for certifying cause of death

(iv) the recording of pathological conditions may be in the wrong order, may contain redundant information, or may be wrong (as judged by subsequent scrutiny). These last errors may indeed be the result of relegating without guidance the job of certifying to the most junior doctor.

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However, he was of the opinion that they affect a relatively small number of certificates, and the errors are not as serious for research and statistics as would appear at first sight.

Adelstein noted that "we should tackle administrative weaknesses such as failure of pathologists to state explicitly causes of death, failure to update after necropsy, and relegation of completion to junior doctors without instruction".

French et al (1978) points out that a poor correlation between the death certificate and hospital notes "can only mean that clinicians do not understand the reports that they receive, or have not attended the necropsy". They recommend that "clinicians should attend necropsies and talk to pathologists".

4.3 Variation in death certification practices

Reid and Rose (1964), in a "pilot inquiry", sent case histories of a representative sample of 10 hospital patients whose deaths had been ascribed to various cardiovascular, renal and respiratory causes to groups of 24 doctors in Boston, 30 doctors in London and 16 doctors in Bergen with the request that they "certify" the cause of death according to their usual conventions. Coding of death certificates was all conducted in London. The overall distribution of deaths by cause was quite similar for the three cities, although there was a tendency for British doctors to use the term "bronchitis" more and for American doctors to use the term "arteriosclerotic heart disease" more than their counterparts.

In 1962-65 the WHO carried out a series of studies in six European countries on the accuracy and comparability of national

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statistics (Anon, 1967). In the first study 1000 death certificates written in English, each with more than one cause of death and chosen so that the underlying cause of death was not obvious, were sent to each of the countries for coding, in some countries by more than one coder. There were marked international differences in coding compared to that made by the WHO Centre for classification of diseases. Finland was the closest, with 90% of deaths coded to the same B-list (50 categories) category of cause of death, and Czechoslovakia the least close, with only 76% the same (for either of two coders). A further study involving 218 disputed death certificates highlighted further international discrepancies in the interpretation of death certificates by coders. The report concluded that "The use of the eighth revision of the International Classification of Diseases, Injuries, and Causes of Death is expected to reduce the number of such discrepancies, but there is also a need for greater uniformity between countries in the procedures adopted if death statistics are to be truly comparable".

Markush et al (1967) obtained a sample of 507 death certificates for November and December 1962 for 12 US states for white men and women aged 30-74, and also obtained details of the smoking habits of the decedents. Arteriosclerotic heart disease deaths were associated with a greater proportion of medicolegal certifiers and of certifier attendance under six months, and with a smaller proportion of certifiers with specialty boards. Smokers and city dwellers were more likely than non-smokers to have their death certified by a doctor who had attended the deceased for less than six months. The authors conclude that comparisons of mortality rates

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for smokers and non-smokers, and for city versus non-city dwellers "may possibly depend upon differences among the certifiers of the deaths". They suggest that "giving more attention to the characteristics of certifiers of deaths would increase the reliability of epidemiological studies of mortality".

Diehl and Gau (1982) sent fictitious case history summaries for 10 "cases" to each of 97 British general practitioners and 26 housemen, and asked them to complete death certificates even if they would have informed the coroner under normal circumstances. No significant variation in the diagnostic groupings reported was found according the doctors' region, type of practice, place of medical training, sex or year of qualification. Doctors qualifying before 1955, however, appeared more inclined than their younger colleagues to list stomach cancer on the death certificate. (The sample size of this study seems too small for reliable conclusions to be drawn.)

In a further paper based on the same study, Gau and Diehl (1982) give the ten case histories (condensed) and the distribution of results provided by the general practitioners for six of the cases, which show quite wide variations. The authors note that "when diagnoses were grouped into broad ICD categories and when the case history concerned only one organ system, 90% of doctors agreed on the cause of death. If more than one organ system was concerned in the case history, however, less than half of doctors were in agreement. The percentage of doctors who elected to inform the coroner also varied widely".

Knight (1986) notes that "there is no doubt that the standard of death certification has fallen in recent years" and that "this

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applies not only to the accuracy of the pathological diagnoses, but to the actual semantics of the entry on the certificates, where the frequent illogicality of the wording can only be ascribed to carelessness and lack of understanding".

Mackenbach et al (1987) sent out sets of case histories to samples of doctors in member countries of the European Community. Their paper concerns 6 histories in which chronic obstructive pulmonary disease was the cause of death and 5 in which cancer was. For both chronic obstructive pulmonary disease and cancer, after certification and coding by national coding offices, an average of 83% of all cases received a correct underlying cause of death code. Errors were due to (i) a false diagnosis in part I of the certificate, (ii) no diagnosis mentioned on the certificate, only signs and symptoms or complications, (iii) the correct diagnosis on the certificate but in part II, and (iv) the correct diagnosis in part I but in a wrong sequence. Some differences in certification practices between countries were compensated for in the process of coding. The authors concluded that their overall results "suggest that differences in certification and coding could in some cases be an important determinant of international mortality differences by cause of death".

4.4 Effect of errors in death certificate diagnosis on lung cancer trends

Gilliam (1955) compared trends in US lung cancer rates observed over the period 1914 to 1950 with those that would have been observed had a proportion of deaths classified as being due to

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tuberculosis or to "other respiratory diseases" actually been due to lung cancer. Although Gilliam noted that differing age/sex-specific trends were not consistent with the whole of the rise in recorded lung cancer rates being an artefact due to past underdiagnosis, he suggests that a substantial proportion of the increase is explained on this basis. He regarded it not unreasonable to believe that 2% of deaths in persons aged 35 years or older that were attributed to "other respiratory diseases" were in fact due to cancer of the lung. If this assumption is correct, it would indicate that the recorded increase in white males since 1914 should be 4-fold and not 26-fold, while the 7-fold increase in females would be reduced to 30 per cent.

The 1977 Report of the Royal College of Physicians (RCP, 1977), in its chapter on lung cancer, contained a discussion on reasons for the rise in recorded lung cancer rates in England and Wales between 1913 and 1973. They noted that "developments in diagnoses took place mostly between 1920 and 1950, with increasing use of chest radiology, bronchoscopy and cytology, and referral of patients to hospital for diagnoses", but that "little" change had occurred over the next 25 years. "Before 1955 very few women aged 65 to 69 had ever smoked cigarettes but between 1916 and 1955 there was a tenfold increase in female lung cancer deaths in this age range ... presumably due chiefly to better diagnosis. This effect would probably have been rather smaller in young patients. If we assume an eight-fold contribution to the increase in the male deaths at ages 35 to 64, the true increase over this period would not have been the reported thirty-fold but probably more like four-fold."

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Silvestri et al (1991) reviewed all 91,336 autopsy records of people dying in the hospitals of Trieste over the period 1901-1985, which formed 53% of all deaths occurring. In 1901 lung cancer accounted for 5.9% of all deaths from malignant neoplasms. The percentage rose to 15% in 1920 and to about 22% in 1950, after which it has remained approximately constant. During this period the frequency with which malignant neoplasms were found at autopsy increased from 9.5% in 1901 to 36.8% in 1985. It is most unfortunate that the authors do not present data on trends in actual age-specific death rates, since a proportion of the rise will be due to the ageing population. Nor do they make any comparison with death certificate data for this period. It is thus not possible, without further information, to compute the proportion of the reported rise in lung cancer that is real, and the proportion that is due to changes in diagnosis.

4.5 Lung cancer as an underlying or contributory cause on death certificates

Sterling et al (1992) analysed a sample of death certificates from the 1986 National Mortality Followback Survey, and from the 1954-62 Dorn Study, a follow-up study of approximately 250,000 holders of US Veterans Life Insurance. Both data sets include information on the smoking habits of decedents and on the underlying and contributory causes of death. Of 235 death certificates among lifelong never smokers, lung cancer was classified as a contributory cause in 62 (26.4%). In contrast, among the 2475 death certificates among current or former smokers, lung cancer was classified as a

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contributory cause in 232 (9.4%). No similar pattern related to smoking was seen for other major causes of death. The authors also noted that where lung cancer is present as a contributory cause, other cancer is much more likely to be present as the underlying cause if the subject had never smoked. The authors concluded that their results "provided evidence of a possible bias because knowledge of a decedent's smoking status appears to influence the designation of lung cancer or some other cancer as the underlying cause or a contributing cause of death. To some extent the biases found in this study multiply with those reported by McFarlane et al (1986) and by Wells and Feinstein (1988). Thus a non-smoker is less likely to have a lung cancer diagnosed in life, and when it is diagnosed, it is less likely to be classified as an underlying cause of death.

5. DIFFERENCE BETWEEN AUTOPSY AND DEATH CERTIFICATE DIAGNOSES

James et al (1955) compared death certificate and autopsy diagnosis in 1889 patients autopsied in 12 hospitals in the Albany, New York region in 1951 and 1952. A preliminary study had shown only a very low frequency of differences in coding autopsies between the three reviewers in the study. Dividing the cause of death into 30 categories there was agreement between death certificate and autopsy diagnosis in 71.0% (1341). The number of patients classified as having died of malignant neoplasms was 372 by both sources, 37 only by autopsy, and 30 only by the death certificate. From a sample of 98 autopsies it was shown that differences in diagnoses were predominantly due to additional data uncovered at

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autopsy, only 20% of cases being due to the certifying physician making avoidable errors.

Erhardt et al (1959) noted that since 1945 there had been a requirement in New York City to report the results of autopsies to the vital statistics office so that the cause of death as originally reported on the death certificate could be revised accordingly. However, it was clear in 1955 that this requirement was not being fulfilled, only 2796 reports being filed out of 10,599 deaths in which an autopsy was noted on the death certificate as having been performed. Some hospitals filed no autopsy reports at all. There were also a substantial number of reports filed for deaths in which no autopsy was noted on the death certificate as having been performed. Erhardt et al studied 5217 autopsy reports in the year 1956 and found that only 794 (15.2%) indicated amendments in the stated cause of death. For 16,824 malignant neoplasms originally recorded as the cause of death, 186 were removed and 258 were added, yielding a net change of 0.4%. Since the impact on the final statistics was considered to be "practically negligible" the authors did not support the requirement to report autopsy results to the vital statistics office. Instead they recommended that "physicians should be encouraged to review gross autopsy findings before completing death certificates".

Rigdon and Kirchoff (1963) selected 194 cases of malignancies from autopsy records made between 1945 and 1958 at the Department of Pathology, M.D. Anderson Hospital, Houston, and then obtained the cause of death as given on the death certificate. There were 38

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cases (listed in detail) in which the assignment of diagnoses for statistical tabulations after coding from death certificates was different from the death certificate or the postmortem diagnoses.

Rigdon and Kirchoff also cite an unpublished report by Korns and Lintz in 1955 which "concluded from a review of 500 autopsy protocols from five hospitals that there was an 11 to 20 per cent disagreement between the medical statements on death certificates and the pathologic findings at autopsy".

Jablon et al (1966) describe results of a study conducted on the survivors of the atomic bombings of Hiroshima and Nagasaki. During the period 1950 to 1962, 1215 autopsies were performed from a total of 11,151 deaths, a rate of 10.9%. The rate had been much lower (5.9%) in the period 1950-1960, when autopsies had been conducted much more frequently in subjects who died in hospital, had malignant disease, were younger, and had lived less than 2000 metres from the hypocenter. Subsequently an attempt was made to gain permission for autopsy in all deaths and the rate rose to 34.8%, the trends noted previously being reduced. 393 autopsies found malignant neoplasms to be the underlying cause of death, agreeing with the death certificate in 305 cases. There were a further 33 malignant neoplasms on the death certificate not confirmed by autopsy. Of 53 cases of cancers of the respiratory system seen at autopsy, 26 were reported on the death certificate, the remaining 27 being divided into 7 where cancer of another site was listed and 20 where no malignancy was listed (including 10 tuberculosis). 6

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cases reported on the death certificate as having died of cancer of the respiratory system were unconfirmed by autopsy, 2 of which had no cancer at all.

Abramson et al (1971) compared death certificate and autopsy diagnosis for 476 deaths occurring in patients aged 15 years or older at the Hadassah University Hospital, Jerusalem during 1963-66. Malignant neoplasm was confirmed at autopsy in 163 deaths. Of these the death certificate reported 130 as an underlying cause and a further 8 as a contributory cause. There were an additional 3 cases reported as an underlying cause and 8 cases reported as a contributory cause not confirmed by necropsy. Of 18 lung cancers seen at autopsy, 10 were correctly diagnosed on the death certificate (9 of which were considered to be the underlying cause), 4 of the remaining 8 mentioning another neoplasm on the certificate. All cases considered to be the underlying cause on the death certificate were confirmed at autopsy in terms of the ICD 4-digit category.

Steer et al (1976) compared death certificate and autopsy diagnosis of cancer in 3708 autopsies conducted on deaths occurring in the Hiroshima/Nagasaki atomic bomb survivors over the period 1961 to 1970. There were 962 cases where cancer was reported on both death certificate and autopsy, 294 where it was reported on the autopsy only, and 60 where it was reported on the death certificate only. The detection rate of autopsy defined cancer was thus 76.6%. It was markedly higher for deaths occurring in hospital (80.6%) than for deaths occurring at home (66.9%). The detection rate was markedly lower in those dying at age 80+. For lung cancer there

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were 112 cases reported on both death certificate and autopsy, 80 reported on the autopsy only, and 20 reported on the death certificate only. The detection rate, 58.3%, was again higher for deaths occurring in hospital (68.0%) than for deaths occurring at home (39.1%). The rate dropped with age to 7.7% in home deaths of 80+ year olds. Of 22 deaths seen at autopsy in 80+ year olds, only 5 were lung cancer recorded on the death certificate.

Clarke and Whitfield (1978), during a study of deaths in medical inpatients in the UK aged under 50, compared death certificate with necropsy diagnosis in 94 patients. There was complete agreement in 47% (44), a minor discrepancy in 24% (23) and a major discrepancy in 29% (27). Rates of agreement were similar for hospital and coroner's necropsies.

Engel et al (1980) assessed the accuracy of certification of underlying cause of death in a study of 257 autopsied cases collected during 1970 at a hospital in Atlanta. 108 (42%) of the cases were found to have the underlying cause of death improperly recorded, and would have altered mortality statistics. Of 83 deaths classified at autopsy as due to malignant neoplasms, 71 were classified as cancers on the death certificates, and there were a further 3 deaths classified as cancer on the death certificates but not confirmed by the autopsy findings. Of 9 cases of lung cancer diagnosed at autopsy, only four were recorded on the death certificates.

Schottenfeld et al (1982) compared autopsy and death certificate diagnosis for 575 consecutive autopsies in 1977 and 1978 at two hospitals, presumably in New York. The death certificates

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were confirmed as accurate in 73.9% (425), as inaccurate but requiring no major coding change in 10.8% (62) and as erroneous and requiring major coding changes in 15.3% (88). The rate of erroneous death certificates was much higher in the community hospital (23.6%; 54/157) than in the university hospital (9.8%; 34/268). A major reason for this difference is that in the university, but not the community hospital, it was the practice to complete the death certificate after the autopsy. There were 160 death certificates coding neoplasms as the underlying cause. The autopsy deleted 9 of these, but added 7 new subjects previously certified as having died of other diseases.

Kircher et al (1985) described a study in which a comparison was made of the underlying cause of death as recorded on the death certificate (DC), as based on a nosologically coded autopsy (NCA), and as reported by an independent pathologist on the basis of his own interpretation of the clinical and pathological material available in the autopsy protocol (CPC). The study was based on a representative sample of 272 autopsies taken from 3,884 autopsies out of 28,440 deaths in Connecticut during 1980. NCA and CPC classifications were made blind of the result of DC. The major findings of the study related to comparison of the DC and NCA classifications. Of the 272 autopsies, 79 disagreed as to the major cause (based on a 17 major category classification), and a further 72 disagreed over the exact disease. The level of disagreement, at 56%, was noted to be rather higher than found in a number of previous studies. Correlation between NCA and CPC was better than that between DC and NCA. However, even here, out of the 272 deaths,

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there were 46 (17%) disagreements about the major disease category and 57 (21%) disagreements about the specific disease. No mention was made of lung cancer in the paper.

Delendi et al (1991) collected information from Trieste, Italy over the period 1970 to 1984 on cases in which lung cancer was diagnosed either on the death certificate or on the autopsy. Trieste is unusual in that unselected autopsies are carried out for more than 97% of all hospital deaths and for about 68% of all deaths in the Province. Of 2563 cases where an autopsy had been carried out, there was complete agreement in 1515 (59%), with the lung cancer being diagnosed only on the death certificate in 292 and only at autopsy in 756. Complete agreement was less frequent in females (40%) than in males (63%), and reduced substantially with age. It did not change materially over the period of the study.

6. DIFFERENCES BETWEEN CLINICAL AND DEATH CERTIFICATE DIAGNOSIS

Macdonald (1938) obtained information from family, doctors, hospitals and social workers in relation to 2033 patients with a death certificate diagnosis of cancer in Massachusetts in 1932. The verified diagnosis was in complete agreement with the death certificate diagnosis in 1590 (78.2%). Of 45 deaths certified as from cancer of the lungs or pleura, there was complete agreement in 32 (71.1%).

From data collected in a survey of the incidence of cancer in ten urban areas of the USA, Dorn and Horn (1940) compared the diagnosis obtained from physician or hospital records with that recorded on the death certificates for persons dying during 1937.

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Data were available for 13,524 cases. When the cases were grouped by primary site into nine broad categories there was agreement in 84.5% between the medical records and the death certificates. Of 602 cases with cancer of the lungs or pleura according to the records, 193 (32%) were classified otherwise on the death certificate (using a detailed site classification). Of the 193, 43 were classified as dying of non-malignant disease, 104 as dying of cancer of other respiratory sites and 46 as dying of cancer of other sites. The authors note that the classifying of 104 cases as cancer of other respiratory sites on the death certificates is due to "the fact that many physicians use the terms 'cancer of the lung' and 'bronchogenic carcinoma' synonymously. The coding rules, however, place 'bronchogenic cancer' in the 'other and unspecified' category".

Dorn and Cutler (1958) reported results of a further study conducted in 1947 along the lines of the earlier (1937) study reported in Dorn and Horn (1940). Of the 22,681 cases indicating cancer as the primary cause of death in the case reports, there was agreement as to specific site in 76% of death certificates, while 6% of death certificates indicated the same major site but a different specific site, 12% indicated a different major site group, and 6% indicated the primary cause was not cancer. Of 2020 case reports with lung cancer as the primary site, there was agreement as to the specific site in 87% of death certificates. One per cent of death certificates indicated the same major site but a different specific site, 7% indicated a different major site group and 5% indicated the primary cause was not cancer. In comparing 1937 with 1947 data, Dorn and Cutler noted that the greatest improvement in agreement

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with respect to specific primary site occurred among respiratory system cancers, 68% in 1937 and 84% in 1947. This occurred because in 1937 "bronchogenic cancer" was coded to "other and unspecified respiratory cancer" but in 1947 it was coded to cancer of the "lung and bronchus".

Moriyama et al (1958) reviewed a sample of 1837 deaths occurring in Pennsylvania during 1956 certified as being of various causes including malignant neoplasm. Questionnaires were sent to physicians signing the death certificates asking for information on diagnostic methods and findings on which the death certification was based, an expression of certainty of the diagnosis entered, and a revised certification if his opinion had changed since signing the death certificate. When the certifier indicated his source of information was another physician, a query was sent to that person as well. Of 443 deaths from malignant neoplasms, the quality of supporting diagnostic information was found to be "very good" (autopsy, operation, microscopic confirmation) in 68.4%, "good" (positive cytology) in 12.9%, "sketchy" (clinical impression, suggestive X-ray findings) in 15.3% and "no report" in 3.4%. For the 54 certificates with lung cancer, the percentages were "very good" 61.1%, "good" 20.4%, "sketchy" 14.8% and "no report" 3.7%. The death certificates were also rated with regard to the diagnostic evidence. For the deaths certified from malignant neoplasms, the evidence indicated this was the "most probable diagnosis" in 85.8%, "another diagnosis equally probably" in 5.0%, "another diagnosis preferred" in 5.6%, and "no diagnostic information" in 3.6%. For lung cancer, the four percentages were 87.0%, 5.6%, 1.9% and 5.6%. For all

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diagnoses considered, where the physician was "positive" about the diagnosis (1032 cases) the reviewer considered the evidence to be "solidly established" in only 61.2% of cases, a reasonable diagnosis in 27.4%, and to be "in doubt" or "probably wrong" in 11.3%. Where the physician was less certain the reviewer was more likely to think the diagnosis was "in doubt" or "probably wrong".

Bonser and Thomas (1959) obtained death certificates for 1036 deaths recorded in Leeds in 1950-54 and coded as cancer of the trachea, pleura, lungs or bronchi, and traced the clinical records of all but 37. Of the remaining 999, 35 were incorrectly certified - 9 were not cancer at all, 3 were cancer of another site without lung metastasis and 23 were cancer of another site with lung metastasis. Many of these errors related to not taking autopsy information into account, perhaps because the certificate was issued before the autopsy was done. Autopsies had been carried out for 294 of the patients with a death certificate diagnosis of lung cancer (etc.). In 169 it confirmed the clinical diagnosis, in 98 it revealed the condition for the first time, and in 27 it demonstrated that the death certificate had been incorrect.

The authors also obtained the clinical notes of 879 cases of lung cancer (etc.) recorded in the admission index of the two main hospitals in Leeds over the same period and related them to the death certificate diagnoses. Sixty-six (7.5%) were either not certified or not coded as cancer of the lung, although the diagnosis was proved at autopsy in 44 and the other 22 were judged clinically to be certainly due to this cause.

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Haenszel et al (1961), for a ten percent sample of all white male lung cancer deaths in the United States during 1958, obtained additional diagnostic details from certifying physicians. Of the 2381 lung cancer deaths in the sample, 1820 (76.4%) were considered to be "well established" in the sense that microscopic evidence was available. These included 656 where an autopsy involving the microscopic examination of the lesion was the basis for diagnosis, 625 where the basis was biopsy of a surgical specimen, 288 bronchoscopy with biopsy, 112 aspiration biopsy, and 139 biopsy of a metastatic site. Excluding the last two categories, 66% of diagnoses were based on tissue from the primary site. The percentage of certifications which were "well established" dropped markedly with age, from about 85% in 35-64 year olds to 49% in those aged 75 and over. It was also lower in non-metropolitan than metropolitan counties though in this case, the difference was relatively minor. For a sample of 247 deaths, the certifying physician was asked to indicate the source of his information and a query was sent to the original source. Only in 162 deaths (66%) did the two sources agree as to either broad histological type or the fact that no microscopic examination had been conducted. In 62 deaths (25%) the two sources agreed as to the fact that microscopic examination had been done, but differed as to the histological type (resulting in a substantially larger number of cases of adenocarcinoma reported by the certifying physician, 54, than by the primary source, 32). In the remaining 23 deaths (9%) the two sources did not even agree as to whether microscopic examination had been conducted.

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Barclay and Phillips (1962) studied 7146 Saskatchewan deaths during the period 1950-56 for which cancer was a primary or contributory cause on the death certificate. For 812 of these the diagnosis was not confirmed from hospital or cancer registry records (11.4% overdiagnosis). There were an additional 1162 decedents where cancer was known to be present but it did not appear on the death certificate (14.0% underdiagnosis). For lung cancer the percentages were 13.6% (96/708) overdiagnosis and 2.7% (20/728) underdiagnosis.

Lombard et al (1962) studied the deaths of all 13,307 patients admitted to Massachusetts cancer clinics from 1946-1958 who died after 1948. Of 860 patients considered by the clinic to have died of lung cancer, 219 were classified on death certificates as dying of primary lung cancer (ICD 162), 569 as dying of lung cancer unspecified as to primary or secondary (ICD 163), with 72 certified as dying of other cancer or non-cancer causes. Of 34 who died with but not of lung cancer, none were certified as dying of an ICD 162 or ICD 163 primary. Of 15 who died apparently cured of lung cancer, only one was certified as dying of lung cancer (ICD 162). Of 12,337 who died and never had lung cancer, 49 were coded as ICD 162 and 126 as ICD 163. Thus 176 out of 964 (18.3%) of deaths on death certificates coded as ICD 162 or ICD 163 were not considered to be lung cancer deaths by the clinics.

Lombard et al comment that deaths coded under the Sixth Revision of the International Statistical Classification of Diseases, Injuries, and Causes of Death are unsatisfactory for epidemiological studies of cancer. "No one can doubt that a man who

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shoots himself while he has a lung cancer is a suicide, but the epidemiologist who wishes to study a possible relationship of cigarette smoking with lung cancer would rather consider this a death from cancer than a noncancer death. The small number of cancer patients who commit suicide would make this matter seem academic were it not for the fact that cerebral hemorrhage, coronary thrombosis, and pneumonia frequently supersede cancer as a cause of death and similarly affect the coding."

McKenzie (1956) sent a questionnaire from the General Register Office to the certifying medical practitioner in respect of every second death ascribed to cancer of the lung or bronchus in January 1955. From 770 inquiries, 654 replies were received. In 20 cases confirmatory procedures had not been adopted to check the diagnosis. Of the remaining 634, the certification of lung cancer was not supported in 18 - in 8 the lung was not carcinomatous and in 10 it was secondary to a primary elsewhere.

Alderson and Meade (1967), based on 1216 deaths in Oxford in 1962, studied the frequency with which death certificates disagreed with hospital diagnoses. For 269 patients with an underlying cause of death of malignant neoplasm according to the hospital records, 11% were coded differently on the death certificate. For all 1216 deaths diagnoses were in error 43% of the time. The 43% error rate was rather higher in older patients (80-89: 52%) than in younger patients (0-39: 35%). The records of 105 were examined in greater detail independently. Errors in the hospital diagnosis were present for 14 (13%) and in the death certificate for 23 (22%). In only 39 out of 105 did the 3 assessments completely agree.

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Puffer and Griffith (1967) conducted an investigation of a total of 43,298 deaths occurring among 15-74 year olds in 12 cities (Bristol, San Francisco and 10 in Central and South America). Death certificates were available for all subjects, and clinical and autopsy data were also collected (13,267 autopsies had been conducted). Two reviewers considered each case, each assigning a weight of 3 if confident about the cause of death, or weights of 1 and 2 if two or more possible causes were involved, 2 being assigned to the more likely. On review it was considered there were 8737 deaths from malignant neoplasms and 1122 from lung cancer (65% based on autopsy or microscopic confirmation). The main objective of the study was to examine geographical variations in mortality after eliminating differences in death certification and coding practices, but extensive tabulations were presented showing, for each city and for 74 causes of death, the number of cases as recorded on the death certificate, the number of exclusions and additions on review, and the final total. Overall review resulted in a change of classification of the cause in 33% of deaths (ranging from 45% in Cali to 22% in Bristol). The detailed results for lung cancer are shown in Table 3. The authors note that the agreement between the original and final assignments was high for lung cancer, with 12% (132) of the 1122 final assignments not originally classified to the site, and of the 1073 initially classified to lung cancer only 7% (83) being subsequently eliminated. More details of the background to and design of this study are given in Puffer et al (1965).

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TABLE 3

Changes in lung cancer diagnoses following review from Puffer and Griffith (1967))

City	Total deaths	Numbers of lung cancers* Original	Exclusions	Additions	Final	Final (%)
Bogota	3629	30	6.7	6.5	29.8	0.82
Bristol	4262	267	7.3	34.0	293.7	6.33
Cali	3298	37	10.7	4.0	30.3	0.92
Caracas	2999	76	4.8	5.3	76.5	2.55
Guatemala City	3422	19	5.0	7.5	21.5	0.63
La Plata	3556	214	8.7	13.4	218.7	6.15
Lima	4378	80	7.3	13.6	86.3	1.97
Mexico City	3541	33	6.5	5.5	32.0	0.90
Ribeirao Preto	1016	12	0.2	1.0	12.8	1.26
San Francisco	3865	157	4.4	18.4	171.0	4.42
Santiago	4321	74	10.7	14.5	77.8	1.80
Sao Paulo	4361	74	10.8	8.3	71.5	1.64
Total	42648	1073	83.1	132.0	1121.9	2.63

*Decimal points arise because of weighting system used (see text).

Steinitz and Costin (1971) compared the numbers of deaths from cancer by site, sex and age in 1964 and 1965 in Israel as recorded on vital statistics, based on death certificates, and in the national cancer registry. For all cancers 2413 deaths were recorded in males and 2484 in females in vital statistics but the cancer registry recorded more, 2734 in males and 2737 in females. For lung cancer (recorded as primary or unspecified as to primary or secondary) there were 436 male and 142 female deaths in vital statistics and 485 male and 172 female deaths in the cancer registry.

De Faire et al (1976) obtained hospital records, autopsy protocols and other available information from 1156 of 1290 deaths occurring during the years 1961-1973 among twins in the Swedish Twin Registry born in 1901-1925 and compared diagnosis of the underlying

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cause with that given on the death certificate. 389 twins were considered to have died from cancer of any site, the death certificate agreeing in 382 and not reporting death as from cancer in 7. There were also 2 deaths where only the death certificate considered cancer had caused death. All 43 cases of cancer of the lung seen in the records appeared on the death certificate, and there was an additional case on the death certificate that was not confirmed.

In the study of Clarke and Whitfield (1978) - see section 2.10 - a comparison of death certificate and clinical diagnosis was also carried out for a further 97 patients for whom no necropsy was available, there was complete agreement in 56% (54), a minor discrepancy in 32% (31) and a major discrepancy in 12% (12). It was noted that the facility for adding supplementary evidence to the death certificate was used in 14 of the 191 cases - in 9 on the basis of subsequent necropsy evidence, in one on biopsy findings, in one a radiological diagnosis, and in 3 as a result of "second thoughts". Of the 21 amendments made in respect of these 14 patiients, 4 were of value, 10 were of no value, and 7 were wrong.

Based on computer linkage of death records and hospital discharge abstracts, Gittelsohn and Senning (1979) compared cause of death and discharge diagnoses in 9724 Vermont hospital deaths occurring in 1969-1975. Comparing the underlying cause of death with the closest hospital record, 72% were found to agree on 3 digit ICD code and 10% on 2 digit code. Concordance was found to decline by patient age and length of hospital stay and to vary significantly by hospital of death and cause. Of 1557 cases with a neoplasm coded

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as the underlying cause of death, 77% had a hospital record diagnosis referring to the same specific site, 21% a diagnosis of neoplasm of a different site, and 2% had no hospital diagnosis of neoplasm. Of 511 cases coded as dying of lung cancer, 11% had a hospital record diagnosis referring to cancer at a different site and 2% had no hospital diagnosis of any neoplasm. Detailed tabulations are presented for many other diseases.

Based on deaths occurring in the Third National Cancer Survey in 1970 and 1971, Percy et al (1981) compared the site of cancer in 48,826 cases where the death certificate had an underlying cause of death of cancer and the hospital diagnosis was of a single primary cancer. Using a 30-site grouping of the cancers, 13.3 per cent had a different site reported on the hospital diagnosis than that indicated by the death certificate. Using a 49-site grouping, the disagreement rate rose to 17.3%. Of 10,178 deaths with cancer of the trachea, lung or bronchus as the cause of death, 618 did not have this site indicated in the hospital diagnosis. In addition there were a further 499 where cancer of the lung (etc.) was the hospital diagnosis but did not appear as the cause of death on the certificate. The paper gives full details of which other cancers were involved for disagreements involving lung cancer, and also for all disagreements involving other cancers.

Selikoff (1992) notes that "there has long been evidence of frequent inaccuracy of death certificates, with significant discordance between such designations and clinical and autopsy data", and cites numerous articles in support of this view. His paper is concerned particularly with use of death certificates in

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occupational studies. In a further paper in the same issue of the American Journal of Industrial Medicine, Selikoff and Seidman (1992) cite results from an occupational study of insulators with asbestos exposure. They compared numbers of deaths by cause according to death certificate diagnosis with numbers according to the "best evidence", ascertained after review of what autopsy, surgical and clinical material was available. There were substantially more deaths according to the best evidence ascribed to mesothelioma (458 vs. 181 from death certificates) and to asbestosis (427 vs. 201) and somewhat more from lung cancer (1168 vs. 1008). In contrast there were less from "GI cancer extended" (which includes cancer of stomach, oesophagus, colon/rectum, liver, gall bladder and bile ducts), with 269 vs. 324, and less from cancer of the pancreas, 54 vs. 92. The authors emphasize the advantages of using data additional to death certificate diagnosis in occupational studies.

7. GENERAL CONCLUSIONS

Three general conclusions merit stressing. Firstly, lack of autopsy is only one of several sources of inaccuracy and inconsistency in relation to death certificate data, and autopsy, by itself, does not ensure 100% accuracy even if clinical history is taken into account and if autopsy findings are accurately reflected on certificates. Secondly, notwithstanding the existence of other sources of inaccuracy, autopsy offers the possibility of substantially improving the level of accuracy of death certificate data over and above that achievable on the basis of clinical diagnosis only. Thirdly, in practice, advances in clinical

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diagnostic techniques seem not to be compensating for the increasing inaccuracy stemming from declining autopsy rates.

In this review I have focussed on only one particular disease, namely lung cancer. There is good reason to believe, however, that the conclusions drawn would have been similar for many other internal neoplastic and non-neoplastic diseases.

Particularly worrying is the evidence only just touched upon here and there in the present review that diagnoses of causes of death entered on death certificates are clearly influenced by fashions and by the particular interests and perceptions of certifying doctors. For instance, knowledge that a person is a smoker affects diagnostic procedures with the result that lung cancer in a non-smoker is less likely to be detected clinically than it is in a smoker.

The continuing inaccuracy of mortality data based on death certification records should be a matter for great concern, both among epidemiologists and among those who determine public health policies. In particular, health authorities should make more resources available for the provision of an expanded and more efficient autopsy service.

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